

# Patient-centred care after Shipman

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PIONEER LECTURE HELD TO HONOUR SIR DONALD IRVINE, FORUM ON QUALITY IN HEALTHCARE, 13 JANUARY 2004

The inquiry chaired by Dame Janet Smith has determined that Harold Shipman unlawfully killed 215 patients, and in a further 45 there were reasons for being concerned about the true cause of death.<sup>1</sup> A statistical analysis gives a figure of 236.<sup>2</sup> The first definite killing was in March 1975; the last was in June 1998. On average, there were around 10 killings a year, but the number was highly variable. Between 1990 and 1993 he killed only 3 people, but in 1996 he killed at least 30, and in 1997 at least 37, a rate of one killing every ten days.

Yet even then, no concerns were raised officially until a courageous doctor from a neighbouring practice, together with her partners, began to think the unthinkable. In March 1998, by which time he had already killed well over 200 people, a police investigation was begun—but quickly abandoned. It was not until Shipman decided to forge the will of one of his victims in June 1998 that a thorough investigation took place, leading to his arrest three months later.

Since beginning to investigate Shipman in 2000, I have been trying to understand how it was that he could kill so many patients without detection. There were, of course, some system failures, but it has been impossible to avoid the question as to why the system weaknesses were tolerated to the extent that Shipman was able to murder not merely one or two patients, but over 200. The conclusion I have come to is that all doctors, and not general practitioners alone, share responsibility for creating the circumstances that enabled Shipman to be so successful a killer. We must accept that responsibility, and embark on a process of professional renewal in which the principle of patient-centredness is given greater force by the addition of the idea of the patient as the source of control.

## SYSTEMS THAT FAILED

One of the system failures was in death certification. By relying on the information provided by a single doctor, and without routine verification of that information, Shipman was allowed to give almost any cause of death. On at least one occasion he certified the cause of death as 'natural causes', without any other details. But Shipman's

completion of death certificates must be seen against a general background of often less than satisfactory certification practice. Dame Janet has concluded that 'certain doctors appear to think that their duty of certification is to some extent discretionary', and that some give an inaccurate cause of death in order to avoid referral to a coroner or to avoid distress to relatives, and that doctors receive insufficient training in the completion of death certificates.<sup>3</sup>

Cremation certification involves the report of the attending doctor (Form B) being checked and confirmed by a second doctor on Form C, and then checked again by the medical attendant (Form D). In reviewing the role of doctors in Hyde who signed Form Cs for Shipman, Dame Janet found that doctors had failed to perceive that the purpose was to provide an independent check on the Form B doctor, and that this responsibility had been discharged in a cursory way. However, she refrained from direct criticism of the doctors concerned because 'in this respect, the Hyde doctors were no worse than countless of their colleagues elsewhere in the country'.<sup>4</sup> This view is supported by the findings of an audit undertaken in the late 1990s at a crematorium in the north of England.<sup>5</sup> Only 42% of 827 Forms B and C had been completed accurately, and 451 generated queries. The authors of the audit remarked that 'doctors seem not to pursue their responsibilities as they once did'.

Shipman did not maintain a controlled drugs register, and claimed that he did not carry opioids. The routine inspection of general practice drug registers and storage facilities had lapsed, and there was no system in place to track the use or disposal of drugs after dispensing. Consequently, Shipman had little difficulty in illicitly obtaining sufficient diamorphine to kill over 200 people through prescription fraud and the appropriation of unused diamorphine from patients or their families.

Some people did make complaints against Shipman. To the best of my knowledge, these included an upheld complaint for failure to visit in 1992, and another in 1995 about incorrect treatment that was not pursued. In 1989, a case of negligence was settled by the payment of a six-figure sum. A complaint in 1985 also reached the General Medical Council (GMC). None triggered a detailed assessment of Shipman's clinical performance. Furthermore, the pattern of complaints was never identified. No single agency had

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responsibility for identifying and recording them all. The unconnected systems for dealing with complaints worked to protect Shipman from detection, rather than protect his patients from harm.

In addition to system failure, some systems that might have protected patients were non-existent. There was no system to monitor mortality rates, and no system for assessment of the standard of records or the recorded care given to deceased patients. Finally, there was no satisfactory system to provide adequate objective evidence about performance. Appraisal and revalidation were not in operation, clinical audit was voluntary and limited in focus, and only a restricted range of routine data were available—for example, prescribing and referral patterns.

The environment—or culture—was also deficient. The group practice in Hyde operated largely as six single-handed doctors working in the same partnership, and whilst this provided a highly personal service, the opportunities for informal peer review were restricted. When he moved to the single-handed practice, Shipman was even more protected from review by colleagues. It was virtually impossible for his employed team of nurses and clerical staff to recognize what was happening, let alone challenge him when patients died unexpectedly. Community nurses and health visitors also lacked the information and authority to challenge him. In the community, people who may have had concerns did not feel able to raise them: a taxi driver who noticed that many of his elderly clients who were Shipman's patients died unexpectedly, and a funeral director who noticed that many of Shipman's patients had been found dead, dressed, sitting in chairs, in the afternoon, could not at first believe there was a problem and later did not believe that anyone would listen. When given the opportunity to raise the alarm in 1994 in the case of a woman admitted after the inappropriate administration of diamorphine, hospital services did not raise concerns with the primary care trust (PTC) or the GMC.

There was, then, a failure of some systems, an absence of other potentially useful systems, and a culture that served to inhibit both suspicion in response to unusual events and the expression of concern if any suspicion did arise. In considering the underlying reasons for this combination of factors and what should be done in response, I will deal with issues at the level of the individual patient and doctor first, and then the level of the public and the medical profession in general.

### THE PATIENT-DOCTOR LEVEL

Shipman's relationship with his patients may be characterized as paternalism on his part and deference on theirs. In the local healthcare community, including nurses, pharmacists and funeral directors, he was regarded as a caring

doctor of the old school—dependable, direct, and always available. In a relationship of paternalism and reciprocal deference, it is easy for the doctor to dominate and even deceive the patient, unless there are external arrangements for detecting such breaches of trust. But there were no adequate external arrangements, and Shipman exploited the situation and his patients with extraordinary ease.

Patient-centredness is regarded as a central feature of general practice, and several initiatives in recent years have sought to build on this beginning—for example, the promotion of patient involvement, or the 'expert patient' initiative. But these developments have not prevented Angela Coulter from saying that paternalism 'is still the defining characteristic of medical care in the British NHS';<sup>6</sup> nor prevented Ian Kennedy from recommending in the report of the Bristol Inquiry that 'The notion of partnership between healthcare professional and the patient, whereby the patient and the professional meet as equals with different expertise, must be adopted by healthcare professionals in all parts of the NHS, including healthcare professionals in hospitals';<sup>7</sup> nor prevented the Department of Health admitting in the *NHS Plan* that 'The relationship between service and patient is too hierarchical and paternalistic.'<sup>8</sup>

It appears, therefore, that the problem of the paternalistic doctor-patient relationship has not been confined to Shipman. But Shipman has shown all too clearly how this type of relationship is open to abuse. The term patient-centredness has been in use for over twenty years without bringing an end to inappropriate paternalism. Indeed, Shipman used elements of patient-centred behaviour to conceal his true intentions. Consequently, it is time to consider whether a more challenging approach to the doctor-patient relationship should be adopted. The idea of the autonomous patient is an alternative,<sup>6</sup> but it deals with only one side of the doctor-patient relationship. The idea of the patient as the source of control comes from the Institute of Medicine's Committee on Quality of Health Care in America, and it is certainly a challenging concept.<sup>9</sup> With the patient as the source of control, the doctor must surrender a degree of control and autonomy. This does not imply that patients must be involved in decision-making against their wishes, nor does it mean that doctors should acquiesce to inappropriate patient demands, merely that within the boundaries of good clinical practice that define the exceptions when the patient should not be the source of control, the doctor seeks to deliver care in accordance with the patient's preferences. It also signals explicitly where the real power lies. Perhaps it is time to explore the idea of the patient as the source of control and express the implications in a revised code for clinical practice.

Practical action is required if the doctor-patient relationship is to change. In general practice, the inclusion

of additional information in the record would be a start—for example, about preferences for control over decision-making and the confidentiality of information in the record, preferences for personal, continuing care or quick access, use of e-mail, telephone, text or mail for communication with the practice, sources of additional health information and desire for further information, and preferred language and reading ability.

The patient also needs information about the doctor. Local repute has traditionally been used by patients to select their doctor, and to check whether their doctor's advice is reasonable. But this local network is not always reliable, and it clearly failed in the case of Shipman. The provision of a wider range of information would enable those patients who wished to check whether their doctor was one in whom they could have confidence. There is a trend towards greater release of performance information in the UK,<sup>10</sup> and it is inevitable that there will be greater openness about performance of general practitioners in the future. Published information might include participation in appraisals, information from audits, targets achieved under the new general practice contract and, when available, mortality patterns. Care will be required, however. Information at the individual practitioner level can be difficult to interpret because of case-mix, patterns of work, and the structure of local services.<sup>11</sup> Once the methodological issues have been fully explored, however, meaningful information should be made available to patients.

Greater openness about complaints histories, including those to the GMC or the NHS, or cases of negligence or investigations of suspected poor performance, presents other difficulties. On the one hand, patients could reasonably expect to be informed if their doctor has been subject to a series of complaints and is under investigation, though the consequences are difficult to predict. It may become difficult for doctors who have successfully overcome performance problems to regain the confidence of patients. Nevertheless, in the long term it will be difficult to resist pressure for the release of information about doctors under investigation—therefore, the sooner we start to think about how this could be done the better.

In addition to information about the doctor, the patient needs information for decision-making, and to verify the doctor's advice. Some doctors are already allowing patients direct access to their own records, leading to more accurate records, better informed patients, and greater patient confidence in the doctor.<sup>12</sup> Sources of information other than the doctor for the patient to use in decision-making could be provided in the practice or through e-mail, the internet or other means. Commonly, patients rehearse their consultation in discussion with family or carers. In hospital outpatient departments this function is often fulfilled by a nurse. Resources do not yet allow this support in general

practice, but, in future, primary care nurses or assistants might take on this role. A telephone or e-mail service run by NHS Direct or patient support groups would be an alternative.

The provision of care in the context of a long-term relationship is a core feature of general practice. It allows patient and doctor to develop a better understanding of each other, and if the doctor is competent, promotes the growth of trust. It would be a tragedy if Shipman's murders were to lead to the end of this feature of general practice. The Shipman Inquiry has shown, in a survey of PCTs, that single-handed practices are out of favour; some PCTs have active policies to phase them out. But the problem in Shipman's practice was not single-handed practice but the patient-doctor relationship and the lack of any adequate external monitoring system. An end to paternalism as the routine style of care in the NHS would be one element of a strategy to protect patients from doctors who try to exploit them. The introduction of genuine performance monitoring would be the second element, and if both were in place, patients could continue to have confidence in the long-term clinical relationship based on trust. There was no satisfactory system of external monitoring, a matter which all doctors must address.

## THE PATIENT-PROFESSION LEVEL

What was the role of the doctors and the professional bodies (the Royal Colleges, the BMA and the GMC) in relation to the systems that failed? Collectively, these bodies both represent and influence the attitudes of doctors towards monitoring, regulation, and their responsibilities in the safe operation of systems of care. With regard to death certification, Dame Janet has recommended that a statutory duty should be imposed on doctors to complete the revised death certificate, and that the GMC should impose a professional duty on doctors to cooperate with the death certificate system. Furthermore, a random sample of completed certificates would be subject to investigation.<sup>4</sup> So on this issue, we have been criticized.

Criticism is also difficult to avoid with respect to cremation certification. Admittedly, the weaknesses of the current system have been pointed out by the BMA, and the Home Office has failed to introduce improvements despite the recommendations of several reports in the past three decades. However, the system was not only poor, it was poorly applied, and the professional bodies failed in encouraging doctors to complete certificates with sufficient care and seriousness. Leadership to indicate the importance of completing certificates and training to show how it should be done should have been provided. On this issue, doctors and their professional bodies failed.

The controlled drug system failed. Evidence about the weaknesses of the system is available from a recent study in Leicestershire. In this study,<sup>13</sup> doctors in a sample of practices were interviewed, and their registers and drug storage facilities were inspected. A questionnaire was sent to all other practices in the country. Almost a third of practices had stopped holding a supply of controlled drugs, either because of anxieties about theft or because of concern about the interpretation of the controlled drugs regulations. Most practices would welcome the reintroduction of regular inspection. The confusion about the controlled drug regulations is illustrated by the variety of controlled drug registers in use. Around half the practices had a standard register, often the one published by the National Pharmaceutical Association. However, even when such a register was used, it was often supplemented by informal registers maintained in notebooks and pocket books. Doctors were uncertain about the regulations governing return and disposal of unused drugs from patients, and the majority wanted a local source of advice to help them apply the regulations appropriately. The application of controlled drug procedures has evidently failed general practitioners.

The fragmented routes to making complaints and seeking redress are confusing to patients, and this could deter complaints or cause those who do make a complaint to grow weary. The Commission for Health Improvement's investigation into the Loughborough general practitioner Peter Green concluded that the 'current NHS complaints procedure contributes to a disempowering system for patients and places unreasonable restrictions on them. It lacks an independent lay input in the investigation and analysis and assumes an ability to articulate concerns with a degree of knowledge and perseverance that is unreasonable'.<sup>14</sup> But the complainant has not only to grapple with the NHS system, but must also decide whether to seek redress through the courts, or whether his or her concern meets the criteria set by the GMC for taking action.<sup>15</sup> However, although someone making a complaint has to negotiate something of an obstacle course, we should withhold criticism of doctors and professional bodies until the Shipman Inquiry has completed its review of the complaints systems.

Of the systems that were absent that might have been useful, the absence of a mortality monitoring system can be eliminated as a deficiency due to professional neglect. Methods that would enable meaningful monitoring of mortality in general practice are only just becoming available, and extensive pilot work is still needed. It is not so easy to dismiss the absence of a system to check on the quality of medical records. Shipman's records were very poor. It should not have been possible for a doctor to continue in practice with such poor recording

habits without action being taken. Approval of general practice trainers and several peer review schemes of the Royal College of General Practitioners include assessment of recording, but no such system exists for all general practitioners. In my review of Shipman's clinical practice, I recommended that the procedure for revalidation of general practitioners should include an assessment of a general practitioner's records,<sup>2</sup> but this recommendation has not been implemented. It appears that, despite the introduction of appraisal and revalidation, it will still be possible for a general practitioner to maintain poor records without being required to address the problem.

An increasing range of routine data is being collected, but neither these data nor audit data are yet used within an integrated scheme of assessment by doctors of doctors. Audit has in effect been a voluntary process, and reluctance to take part has been tolerated.

Shipman did not undergo at any time during his career a review of his clinical performance that stood any chance of detecting his murderous activities. If performance assessment cannot detect hundreds of murders, it can hardly be expected to detect lesser performance aberrations. After Shipman, the case for revalidation could hardly be stronger. Revalidation will be a signal to the public from the GMC that a doctor is fit to remain in practice; and, as it was originally designed and intended, an assessment of performance would have been undertaken to determine fitness to practise. Substantial pilot work was undertaken to develop and assess potential methods. However, it is difficult to avoid the conclusion that there has been some retreat from the original intention. Revalidation is to be linked to appraisal, supported by a statement that the PCT has no concerns about the doctor's fitness to practise. Appraisal does not include an objective assessment of performance. A doctor who wished to conceal performance problems at appraisal could probably do so, and by associating appraisal with revalidation, the pressure to conceal problems will be difficult for some doctors to resist. The additional statement from the PCT helps, but only a little, since the PCT will have only a limited range of performance information available, often at practice rather than doctor level. It has taken many years of debate, concluded by the experiences of Bristol, Ledward, Shipman, Green and others, to reach the point at which revalidation became accepted policy. It is disappointing that the system will be less rigorous than was originally planned.

Although the environment or culture was discussed as a factor that enabled Shipman to flourish, this will not be considered in relation to the patient-professional level. The Shipman Inquiry's final report may touch on the issue of culture, and speculation would be premature. It would be

reasonable to limit comments to a quotation from the Bristol Inquiry report:

‘... the culture of the future must be a culture of safety and of quality; a culture of openness and accountability; a culture of public service; a culture in which collaborative teamwork is prized; and a culture of flexibility in which innovation can flourish in response to patients’.

## CONCLUSIONS

The Shipman case has implications beyond adjustment to a limited number of systems. Although reform of some systems is required, including certification, monitoring and complaints, doctors must also confront the deeper issues that allowed these systems to deteriorate and Shipman, the murderer, to prosper. The key issue is how doctors think about themselves in relation to their patients, both at the level of the individual doctor and patient and at the level of the professional bodies. The key task for the profession and its organizations is a process of renewal whereby the interests of patients genuinely come first.

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